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## Legal Reforms and Their Limitations

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### The Law as a Means of Improvement

The law has an important function as a moral teacher, both for the professions and for the general public. Even though they do not always give full effect to the value of self-determination, legal rules and court decisions remind society of its commitment to this value.<sup>1</sup> Beyond this symbolic function, law establishes minimum, enforceable standards for disclosure that enable injured patients to receive compensation for injuries caused by health professionals' failure to meet these standards. Although the existence of this potential liability has generated anxiety among practitioners, it has also spurred valuable reassessment of ethical norms and professional practices and has made practitioners more sensitive to patients' needs and expectations.<sup>2</sup> The Commission firmly believes that the law can and should continue to perform these essential functions.

The Commission appreciates the practical difficulties of adopting its approach to patient-professional relationships as

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<sup>1</sup> See Jay Katz, *Informed Consent—A Fairy Tale?: Law's Vision*, 39 U. PITT. L. REV. 137 (1977); Joseph Goldstein, *For Harold Lasswell: Some Reflections on Human Dignity, Entrapment, Informed Consent, and the Plea Bargain*, 84 YALE L.J. 693 (1975).

<sup>2</sup> From the Commission's survey it is apparent that several aspects of the legal doctrine of informed consent and its implementation (*i.e.*, increased disclosure, increased patient involvement in decisionmaking, and consent forms) have made physicians more sensitive to patients' needs and expectations. As discussed in Chapter Four, these aspects are generally viewed as beneficial to the doctor-patient relationship because they tend to provoke discussion, enhance understanding on the part of both doctor and patient, lead to better decisions, and aid compliance.

the normative legal expectation for informed consent. Transcending these practical difficulties is a more fundamental issue: the Commission is not convinced that its vision of the patient-professional relationship can be achieved primarily through reliance on the law.<sup>3</sup> Having analyzed the relationship in a way that recognizes the complexities and variations of individual cases, the Commission is aware that the informed consent process may not be susceptible to detailed regulation by so blunt an instrument as the law of battery or of medical negligence. Indeed, the Commission is concerned that efforts to draw the law further into regulating the subtler aspects of relationships between patients and health care professionals may prove ineffective, burdensome, and ultimately counterproductive.<sup>4</sup>

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3 One obstacle to the implementation of the Commission's vision through law is the difficulty of formulating an appropriate means of enforcement. When a health care professional does not engage in ethically proper discussion with a patient, and the failure to do so causes no bodily harm to the patient, the amount of damages to which the patient would be entitled are nominal, and thus few if any patients (and lawyers) would be willing to bring suit under such circumstances. Instead of relying on traditional litigation to implement the Commission's vision,

[t]his could be achieved by establishing a system of non-insurable tort-fines for violation of the duty to disclose and a compensation fund. The fines would be paid into the fund, which would be used to compensate those persons the legislature defines as injured by nondisclosure. Under this arrangement doctors are provided with guidance and are subject to specific deterrence. All physicians who violate a duty to disclose would be liable for fines that could be set in accordance with their deterrence objective. Only those patients suffering injury, as defined by the legislature, would be compensated.

Leonard L. Riskin, *Informed Consent: Looking for the Action*, 1975 U. ILL. L. F. 580, 606-07.

4 One unfortunate by-product of the legal regulation, through malpractice suits, of the doctor-patient relationship in an attempt to establish a minimum level of quality in the provision of medical services is practice of what is referred to as "defensive" medicine, which "consist[s] of medically unjustified care provided by the physician for the purpose of reducing the possibility of a malpractice suit...." Project, *The Medical Malpractice Threat: A Study of Defensive Medicine*, 1971 DUKE L.J. 939, 942. This study concludes that "[t]he threat of a malpractice suit does induce physicians to overutilize diagnostic tests and procedures in particular cases, but...the practice is not extensive and probably not a contributing factor to the rising costs of medical care." *Id.* at 964. *But see* Elliot Sagall, *Medical Malpractice: Are the Doctors Right?*, 10 TRIAL (July/Aug. 1974) at 59, 60, suggesting that reports on the extent of the practice of defensive medicine are exaggerated.

Nevertheless, in this Report the Commission has set forth a vision of informed consent that could, if incorporated into state law as cases arise, bring the law closer to its ethical roots as well as to the realities and potentialities of day-to-day health care. Although the Commission does not regard changes in the law as the major way its conclusions about informed consent will be translated into practice, it does believe that it would be appropriate—even desirable—for the law on the subject to adjust its minimum expectations in the direction pointed to in this Report.

Most fundamentally, the law could emphasize the process of continuing communication and decisionmaking, rather than the pro forma disclosure of particular risks that now strikes many practitioners as a hollow charade.<sup>5</sup> Such a shift in focus would make clear that a professional's obligation is not satisfied—and the professional is not insulated from legal liability—simply by obtaining the patient's signature on a consent form.<sup>6</sup> Instead, courts could engage in a more qualitative evaluation of the entire process that would account for the professional's overall effort to elicit matters of particular concern to the patient and to respond to the patient's worries, insofar as reasonably possible, through disclosure and discussion. Instead of focusing, as is now the case, on whether the

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In Texas, informed consent is legally governed by a set of detailed regulations describing what doctors are supposed to disclose for particular procedures. *See* 3 Tex. Reg. 4293-96. §§ 319.01.03.001-.003 (Dec. 12, 1978), issued pursuant to Tex. Rev. Civ. Stat. Ann. art. 4590i, § 6.03 (Vernon Cum. Supp. 1980). The limitations of law in regulation of the relationship between doctors and patients is well developed by Fox and Swazey in their discussion of the famous heart transplant case of *Karp v. Cooley*, 493 F.2d 408 (5th Cir. 1974). *See* Renée C. Fox and Judith P. Swazey, *THE COURAGE TO FAIL: A SOCIAL VIEW OF ORGAN TRANSPLANTS AND DIALYSIS*, Univ. of Chicago Press, Chicago (1974) at 201 *et seq.*

<sup>5</sup> The requirement of informed consent has frequently been described by physicians as a myth or a fiction. *See, e.g.,* Henry K. Beecher, *Consent in Clinical Experimentation—Myth and Reality*, 195 J.A.M.A. 34-35 (1966); Preston J. Burnham, *Medical Experimentation on Humans*, 152 SCIENCE 448 (1966); William P. Irvin, "Now, Mrs. Blare, About the Complications...", 40 MED. ECON. 102 (1963); Eugene G. Laforet, *The Fiction of Informed Consent*, 235 J.A.M.A. 1579 (1976); Edmund B. Middleton, *Informed Consent*, 233 J.A.M.A. 1049 (1975); Mark Ravitch, *Informed Consent—Descent to Absurdity*, 101 MED. TIMES No. 9, 164 (1973). The articles critical of informed consent appear to have diminished in frequency in the last few years.

<sup>6</sup> *See* note 44, Chapter One *supra*. If informed consent is viewed as a process—as this Report envisions—rather than as an event, proposals to embody "informed consent" in a written or "electronic" document are ultimately unavailing. *See, e.g.,* Note, 44 BROOKLYN L. REV. 241, 273-81 (1978).

practitioner warned the patient of risks, courts would inquire into whether or not the practitioner took sufficient steps to involve the patient in the decisionmaking process. The questions before the court could include, for example, whether the practitioner made reasonable efforts to impart information, to determine whether the patient understood it, to elicit the patient's values and preferences, to create a noncoercive atmosphere for the decision, and to encourage the patient to decide on the basis of the available information and the patient's own values.<sup>7</sup>

Efforts to translate the Commission's recommendations of ethical norms for the communication process directly into detailed legal rules may create evidentiary difficulties. To the extent that the issues to be examined in a lawsuit would be more subtle and subjective than they currently are if the Commission's recommendations were to form the ethical basis of law, proof of what occurred would be complicated. Of course, the direct testimony of both professional and patient could provide accounts of the decisionmaking process. Yet as discussed in Chapter One, the tendency of such testimony to be selective and self-serving is familiar and difficult to overcome.<sup>8</sup> Documentary evidence could be introduced as well, but the production of a full documentary record reflecting not merely a formal written consent but the entire process of communication and decisionmaking over an extended time would impose substantial burdens. Of particular concern would be the time needed to generate and ensure the accuracy of such records from the viewpoints of all parties.

The implication to be drawn from these difficulties is not, however, that professionals should comply with the limited requirements of the law, and then go about their business as they see fit. The Commission rejects the attitude that divides obligations into two categories: those that are legally established and must be obeyed under pain of penalty, and those that are not so established and hence can be ignored. Throughout this Report the Commission has employed the

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<sup>7</sup> Several current dilemmas in informed consent law would remain problematic in this view. For example, what causal relationship needs to be established between the professional's failure to provide a basis for effective participation and the physical injury associated with treatment? When the professional's failure to provide such a basis did not result in physical injury to the patient, there would be no readily ascertainable monetary damages to serve as a basis for redress (or to encourage an attorney to take the case on a contingent-fee basis). A standard for money damages to redress dignitary injuries may be needed, or the governmental and voluntary organizations that regulate licensure and certification may need to investigate allegations of systematic violation of patients' rights, as a ground for professional discipline.

<sup>8</sup> See pp. 25-26 *supra*.

terminology of “professional-patient relationships” rather than the language of the marketplace, which treats patients as “consumers,” to underline the importance of recapturing a sense of professional norms and obligations. Such norms are more than gratuitous advice; they are to be taken seriously, both by individual professionals and by their organizations.<sup>9</sup>

In distinguishing between a strictly legal obligation to secure consent and a professional’s broader obligation to provide patients with a basis for effective participation in decisionmaking, the Commission hopes to remind health care professionals that their obligations transcend legal requirements and incorporate objectives that the law cannot readily enforce. The roots of the broader obligation are ethical and reside with the mutual trust and expectations that are appropriate for parties to the relationship. The Commission believes that recognition and fulfillment of these professional obligations by health care practitioners will go a long way toward alleviating the sometimes adversary character that has encroached upon patient-professional relationships in recent years and will reinforce the mutual trust on which successful relationships are ultimately founded.

### **Enhancing Self-Determination of the Formerly Competent**

In addition to any judicial modification in the law of consent to bring it into line with the Commission’s conclusions, states should direct legislative attention to giving patients the means to have at least some say about treatment decisions in the event they become incapable of participating in decisions directly.<sup>10</sup> More than one-third of the public in the Commission’s survey have given instructions (though only one-quarter of those are in writing) to someone about how they would like to be treated if they become too sick to make decisions themselves. While this issue has gained prominence largely because of the attention recently accorded to so-called living wills for dying patients, people can and do set forth instructions to guide a wide variety of health care decisions.

As discussed in Chapter Two, such means would permit two of the goals of self-determination to be fulfilled: individualizing the meaning of well-being and showing respect for personal dignity. The third goal—that a patient be an active

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<sup>9</sup> Indeed, although the broad generalities of battery and malpractice law, which aim largely at redressing past misconduct, may not be helpful here, the rules spelled out by hospital boards, medical societies, and licensing bodies could provide more detailed prospective guidance and encouragement.

<sup>10</sup> Standards and procedures for assessing which patients are incapable of participating in a health care decision are discussed in Chapter Eight *infra*.

agent in decisions about his or her own care—would be impossible to achieve at all in the case of an unconscious patient and impossible to achieve fully with patients who are less seriously incapacitated. Although this Report focuses on patients' direct decisions about their own care, no discussion of legal reforms would be complete without some attention to how a person's informed consent might carry forward to a time when he or she is no longer able to participate directly through the use of written directions (known as "advance directives") prepared in anticipation of some future incapacitating illness.

Without changes in the law, the problem facing a person who wants to direct the care he or she will receive if incompetent is that the authorization provided to a family member or physician ceases to be legally effective at just the time when it is needed, namely when the person becomes incompetent, because of the legal rule (which is quite sensible in other contexts) that an agent's authority is terminated by incompetence of the person who appointed that agent.<sup>11</sup> Thus, special provision must be made if a person's directions about medical care, set down while he or she is competent, are to be effective in determining, or even officially guiding, the decisions actually made if the person becomes incompetent.

**Instruction Directives.** Two types of advance directives have already been recognized by some states: instruction directives and proxy decisionmaking directives. The best known examples of the first type are the "natural death" statutes that have been enacted in 14 states since the first was adopted in 1976 in California.<sup>12</sup> These specify certain circumstances under which a directive to a treating physician (the wording of which is usually set forth in the statute) will be effective in limiting the extent of life-sustaining treatment administered to a patient whose condition has been diagnosed as imminently fatal. Instruction directives are, in theory, limited neither to terminal illness nor to orders to desist from treatment. They could be employed by patients who have been told that they may soon become incapable of making decisions (for example, because of a brain tumor) or by those who simply

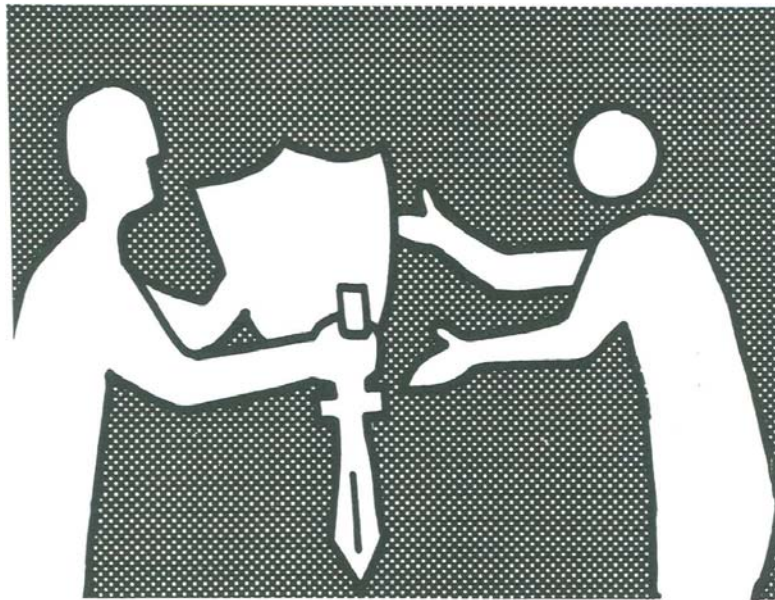
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<sup>11</sup> See American Law Institute, *RESTATEMENT (SECOND) OF AGENCY*, American Law Institute Publishers, St. Paul, Minn. (1957) at § 122.

<sup>12</sup> See Ala. Code §§ 22-8A-1 to 22-8A-10 (Supp. 1981); Ark. Stat. Ann. §§ 82-3801-.3804 (Supp. 1981); Cal. Health and Safety Code §§ 7185-7195 (Deering Supp. 1982); D.C. Code §§ 6-2421 to 2430 (Supp. 1982); Del. Code Ann. tit. 16, §§ 2501-2509 (1982); Idaho Code §§ 39-4501 to 4508 (Supp. 1982); Kan. Stat. Ann. §§ 65-28,101 to 65-28,109 (Supp. 1981); Nev. Rev. Stat. §§ 449.540-.690 (1979); N.M. Stat. Ann. §§ 24-7-1 to 24-7-11 (1981); N.C. Gen. Stat. §§ 90-320 to 90-322 (1981); Or. Rev. Stat. §§ 97.050-.090 (1981); Tex. Rev. Civ. Stat. Ann. art. 4590h §§ 1-11 (Vernon 1982); 18 Vt. Stat. Ann. §§ 5251-5262 (1982); Wash. Rev. Code Ann. 70.122.010-70.122.905 (West 1982).

wish to have “standing orders” about some aspect of their care (such as no blood transfusions). Instructions could authorize the use of certain types of treatments, as in the case of people diagnosed as having progressive senile dementia of the Alzheimer’s type who, before they become incompetent, give their permission for research procedures of more than minimal risk. And rather than specifying that under particular circumstances an individual does or does not authorize a particular type of medical intervention, instructions could describe a person’s attitude toward a particular state of affairs.<sup>13</sup>

Whether the instructions are quite precise or very general, for several reasons an advance directive of this type is of limited use in providing effective self-determination. First, it would be extremely difficult to draft a directive that did not leave considerable range for interpretation; both the existence of the circumstances making the directive effective and the steps to be taken under it will often require discretion by health care professionals and family. Second, if the terms of the document were made more precise in order to leave the choices more with the patient and less with the treating professionals, the range of circumstances to which the document would apply would have to be narrowed or its length and complexity would have to be increased.



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<sup>13</sup> An example of such a directive would be one stating: “I feel that I would rather not live than remain in an unconscious state from which I have no likelihood of recovering.” This might provide a clearer sense of a person’s feelings and wishes than a directive that merely specifies the treatment a person does or does not want under certain circumstances.

Third, and perhaps most important in light of the analysis of informed consent contained in this Report, instruction directives are likely to address only a limited range of medical situations that occur frequently enough to be of general concern to people. Beyond these, a directive would itself be an example of knowing and voluntary self-determination only if it emerged from a patient-professional relationship in which the patient had been counseled about the future risk of a particular disability and about the courses of treatment that would probably then be available. Even then, decisionmaking under an instruction has a truncated quality since the patient will have dictated specific decisions before all the particulars of the situation were clear and before the process of mutual participation and shared decisionmaking had fully ripened. Consequently, such directives are likely to be more useful in excluding certain procedures that are totally unacceptable to a patient than in fine-tuning decisionmaking about a full range of possible health care choices.

**Proxy Directives.**<sup>14</sup> An alternative type of directive, which would avoid the difficulties both of anticipating all possible treatment choices and of leaving full discretion to health care professionals, would designate a person as authorized to make treatment decisions on a patient's behalf under specified circumstances.<sup>15</sup> Both the range of circumstances in which the proxy may act and the range of choices he or she is authorized to make could be broad or narrow. For example, a person who wanted vigorous treatment could authorize a proxy to make all necessary decisions, subject only to the requirement that all therapies be aggressively pursued if they offered any possibility of benefit.

Although a proxy's decisions are not directly acts of the patient, proxy directives meet the objective of allowing patients to limit what happens to them if they appoint proxies with whom they have discussed their views and who are willing to insist on treatment decisions that are consistent with those views. The proxy can participate in the process of shared decisionmaking in the patient's stead, so that that process is

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<sup>14</sup> The term "surrogate" is used in this report (*see* Chapter Eight *infra*) to designate an agent authorized to make a health care decision on behalf of a patient who lacks the capacity to do so personally. Within this category, a "proxy" is a surrogate appointed by a patient.

<sup>15</sup> In the context of the present discussion, the triggering event under a directive designating a proxy would be (at the least) that the signer had become incapable of participating in decisions about his or her own care. Directives could, in theory, designate a proxy to step into the decisionmaking shoes of a person who remained capable of making his or her own choices but who chose not to.



not artificially truncated. The degree to which this proxy process actually substitutes for a patient's direct participation depends upon how extensively the patient had previously talked over the relevant issues with health professionals.

By combining a proxy directive with specific instructions, an individual could control both the content and the process of decisionmaking about care in case of incapacity. The use of instructions would help overcome the open-ended nature of designating a proxy by increasing the likelihood that in the process of deciding on instructions a person would have discussed relevant considerations with both the potential proxy and the health care professionals—in other words, that the person would go through a process of prospective informed consent.

The possibility of appointing a proxy for health care decisionmaking already exists in the laws of 37 states that have adopted statutes authorizing what is usually termed a durable power of attorney.<sup>16</sup> Although these were fashioned over the past 30 years primarily to provide a less expensive means than court-ordered guardianship or conservatorship for dealing with small property interests, there is nothing in the acts that would explicitly preclude the use of durable powers of attorney to designate or instruct a proxy to make health care decisions. Commentators have suggested such use and there is

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<sup>16</sup> See Alaska Stat. §§ 13.26.325, .330 (1979); Ariz. Rev. Stat. §§ 14-5501 to 5502 (1975); Ark. Stat. Ann. §§ 58-501 to 511 (1971); Colo. Rev. Stat. §§ 15-14-501 to 502 (Supp. 1979); Conn. Gen. Stat. § 45-690 (1979); Del. Code tit. 25, §§ 175-180 (Supp. 1978); Fla. Stat. Ann. § 709.08 (West 1980); Ga. Code Ann. § 4-214.1 (1975); Haw. Rev. Stat. §§ 560:5-501 to 502 (Supp. 1979); Idaho Code §§ 15-5-501 to 502 (1979); Ind. Code Ann. §§ 30-2-1.5-1 to 2 (Burns Supp. 1979-1981); Iowa Code Ann. §§ 633.705-.706 (West Supp. 1980-1981); Ky. Rev. Stat. § 386.093 (Supp. 1978); Me. Rev. Stat. tit. 18-A, §§ 5-501 to 502 (1979); Md. Est. & Trusts Code Ann. §§ 13-601 to 602 (1974); Mass. Ann. Laws, ch. 201, § 50 (Michie Supp. 1980); Mich. Comp. Laws Ann. §§ 700.495-.499 (Supp. 1980-1981); Minn. Stat. Ann. §§ 524.5-501 to 502 (West 1975); Miss. Code Ann. § 87-3-15 (1973); Mont. Code Ann. §§ 72-5-501 to 502 (1979); Neb. Rev. Stat. §§ 30-2662 to 2663 (1975); N.J. Stat. Ann. §§ 46:2B-8 to 9 (West Supp. 1979-1980); N.M. Stat. Ann. §§ 45-5-501 to 502 (1978); N.Y. Gen. Oblig. Law § 5-1601 (McKinney 1978); N.C. Gen. Stat. § 47-115.1 (1976 & Supp. 1979); N.D. Cent. Code §§ 30.1-30-01 to 02 (1976); Ohio Rev. Code Ann. §§ 1337.09-.091 (Page 1979); Okla. Stat. Ann. tit. 58, §§ 1051-1062 (West Supp. 1979-1980); Or. Rev. Stat. §§ 126.407, .413 (1979); Pa. Stat. Ann. tit. 20, §§ 5601-5602 (Purdon 1975); S.C. Code § 32-13-10 (Supp. 1979); Tex. Prob. Code Ann. tit. 17A, § 36A (Vernon Supp. 1980); Utah Code Ann. §§ 75-5-501 to 502 (1978); Vt. Stat. Ann. tit. 14, §§ 3-51-3052 (Supp. 1979); Va. Code §§ 11-9.1 to .2 (1978); Wash. Rev. Code Ann. §§ 11.94.010-.020 (Supp. 1980-1981); Wyo. Stat. §§ 34-9-101 to 110 (1977). See also Uniform Durable Power of Attorney Act, 8 U.L.A. 74-80 (1981).

anecdotal evidence that it has occurred, but this use has not been the subject of any reported judicial decisions.<sup>17</sup>

**Statutory Developments.** In addition to the existing statutes that provide a means for patients to create one type of advance directive or another, several model statutes have been proposed specifically to allow such directives in health care.<sup>18</sup> In evaluating existing or proposed means or in devising new ones, several factors need to be taken into account. Four groupings of such considerations are presented here to suggest the range of issues the Commission believes should be addressed in evaluating statutory alternatives.

***Requisites for a valid directive.*** Special attention needs to be given to the basic requisites for a valid directive, particularly since some of the statutes that might be employed—such as the durable power of attorney acts—were not designed specifically for the appointment of proxy health care decisionmakers.

**Decisionmaking capacity of principal:** There should be some way to establish that a person filling out a directive (the principal) was legally competent to do so at the time. The emphasis of this Report (as discussed in Chapters Three and Eight) is on patients possessing decisional capacity rather than on legal competence. Should a statute insist that when a directive is executed the person has the capacity to understand the choice embodied in the directive? To certify a signatory's capacity, statutes often require one or two witnesses to a document. It would seem advisable for a statute to be clear on whether the witnesses must attest to the principal's capacity or merely serve as safeguards against fraudulent signatures. Since such witnesses are likely to be laypeople, the standard of decisionmaking capacity they apply will rest on common sense, not psychological expertise.

**Due regard for the step being taken:** The related concern that everyone involved in the execution of a directive, particularly the principal and the prospective proxy, recognize the seriousness of the step is something that would be more difficult to guarantee by statute. It is, however, a consideration that arises in evaluating the wisdom of using existing durable-power statutes, which were intended to address only property matters. One way to increase the likelihood that due regard is given to the subject matter would be to provide that before a

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<sup>17</sup> *Legal Problems of the Aged and Infirm—The Durable Power of Attorney—Planned Protective Services and the Living Will*, 13 REAL PROPERTY, PROBATE AND TRUST JOURNAL 1, 2-4, 35-36, 41 (Spring 1978).

<sup>18</sup> Yale Law School Legislative Services Project, MEDICAL TREATMENT DECISION ACT, Society for the Right to Die, New York (1981) at § 3; UNIFORM HEALTH CARE CONSENT ACT, National Conference of Commissioners on Uniform State Laws, New York (1982) at § 6; UNIFORM RIGHT TO REFUSE TREATMENT ACT, Concern for Dying, Chicago (Draft, May 1982) at §§ 3-5.

directive is executed, the principal (and proxy, where one is involved) must have had a discussion with a health care professional of the patient's objectives and of the directive's potential consequences. This would also help ensure that any instructions reflect a process of active self-determination on the part of the patient-to-be.

***Legal effect of directives.*** Several questions arise about the effects that a directive should have in the law and about how these effects might be achieved.

**Registration:** Certain documents are officially registered, so that they will not be ignored and so there can be no doubt that all concerned parties are aware of their existence. The process of registration also provides an opportunity to ensure that all the basic documentary requisites have been met; for example, an official who is charged with registering directives could be trained to determine the competence of signers. On the other hand, the additional formality of required registration might seriously discourage the use of directives, and it is doubtful whether in this context—unlike in a commercial or real estate setting—there is really much need for a directive to be on file in a governmental office in order for it to have its desired effect at the time it would be needed.

**Legal immunity:** A statute should make clear that people acting pursuant to a directive are not subject to civil or criminal liability for any action they take that they would not be liable for were they acting on the direct consent of a competent patient. Yet since directives—particularly those including instructions—may contain unavoidable ambiguities, some leeway must be offered if this legal immunization is to provide adequate reassurance for health care professionals. Some of the existing statutes speak of protection for actions taken in “good faith.”<sup>19</sup> Language of this sort provides sensible protection for subsidiary health personnel who follow the orders of the physician in charge of the patient, provided they believe the physician's orders are in line with the directive or have been authorized by a proxy. Some standard of reasonable interpretation of the directive may need to be imposed, however, on an attending physician's reading of the document, lest “good faith” offer too wide a scope for discretion. Such a standard might best be developed in case law and scholarly commentary rather than in the statute itself.

**Penalties for noncompliance:** In order to make directives legally binding, several states have included penalties in their

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<sup>19</sup> See Ala. Code § 22-8A-7 (Supp. 1981); Del. Code Ann. tit. 16 § 2505 (1982); Kan. Stat. Ann. § 65-28,106 (Supp. 1981); N.M. Stat. Ann. § 24-7-7 (1981); Or. Rev. Stat. § 97.065 (1981); Wash. Rev. Code Ann. § 70.122.050 (West 1982). See also MEDICAL TREATMENT DECISION ACT, *supra* note 18, at § 9; UNIFORM RIGHT TO REFUSE TREATMENT ACT, *supra* note 18, at § 12.

statutes (fines, for example, or suspension or revocation of professional licenses) for failing to follow an advance directive.<sup>20</sup> The wisdom or necessity of such penalty clauses depends upon the problem a statute is attempting to remedy. If health care providers are unwilling to share responsibility with patients and, in particular, tend to overtreat patients whose physical or mental condition leaves them unable to resist, then—unless they are made legally binding—advance directives are unlikely to protect effectively patients who want to limit their treatment. On the other hand, if health care professionals are simply unsure of what patients want, or if they are anxious to share decisionmaking responsibility but are apprehensive about their legal liability if they follow the instructions of a person whose decisionmaking capacity is in doubt, then the threat of penalties would be unnecessary. Indeed, it could even be counterproductive if it fostered an adversarial relationship between patient and provider.

***Proxy's characteristics and authority.*** Several special questions arise in the context of health care concerning who may act as a proxy and what the proxy may do.

**Competency of the proxy:** The basic consideration about a proxy is that he or she should have the capacity to make a particular health care decision when needed. The means for assuring this capacity are not so simply stated, however. Basically, they would seem to be the same ones that are applied to patients themselves, as discussed in Chapter Eight.<sup>21</sup>

**Disqualifications:** Another issue, which could also be treated as a prerequisite for appointing a proxy, concerns whether limitations should be placed on who may serve. The main consideration is to avoid the appointment of anyone with interests that are adverse to a patient's. In some "natural death" statutes, this has led to explicit exclusion of anyone financially involved (as debtor, creditor, or heir) with the patient.<sup>22</sup> Special concern may also be warranted for patients in nursing homes.<sup>23</sup> Unfortunately, in the absence of a special

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20 Cal. Health and Safety Code § 7191(b) (Deering Supp. 1982); Kan. Stat. Ann. § 65-28, 107(a) (Supp. 1981); Tex. Rev. Civ. Stat. Ann. art. 4590h § 7(b) (Vernon 1982). *See also* MEDICAL TREATMENT DECISION ACT, *supra* note 18, at § 9; UNIFORM RIGHT TO REFUSE TREATMENT ACT, *supra* note 18, at § 12.

21 *See* pp. 172-73 *infra*.

22 *See* Ala. Code § 22-8A-4 (Supp. 1981); Cal. Health and Safety Code § 7188 (Deering Supp. 1982); Del. Code Ann. tit. 16, § 2503(b) (1982); Idaho Code § 39-4505 (Supp. 1982); Kan. Stat. Ann. § 65-28,103(a) (Supp. 1981); Nev. Rev. Stat. § 449.600 (1979); N.C. Gen. Stat. § 90-321(c) (1981); Or. Rev. Stat. § 97.055 (1981); Tex. Rev. Civ. Stat. Ann. art. 4590h § 3 (Vernon 1982); 18 Vt. Stat. Ann. § 5254 (1982); Wash. Rev. Code Ann. § 70.122.030 (West 1982).

23 *See, e.g.,* Cal. Health and Safety Code § 7188.5 (Deering Supp. 1982): "A directive shall have no force or effect if the declarant is a patient in

group of people who serve as proxies for patients there, the people most readily available—the nursing staff and institutional officers—are typically not disinterested.

Redelegation: In certain circumstances a proxy may be temporarily or permanently unable or unwilling to serve as a substitute decisionmaker. When that occurs, should alternate proxies be limited to people who were named by the principal in an original or amended directive, or, in the absence of such alternates, should a proxy be allowed to delegate his or her authority to another person of the proxy's choosing?<sup>24</sup> This issue might be affected by whether either the original or a substitute proxy was a close relative of the patient, as opposed to a stranger.

Access to information: Since the proxy stands in the shoes of the patient and is expected to engage in a comparable decisionmaking process, logically the proxy should have access to the patient's medical record. Yet it may be advisable to limit the proxy's access only to that information needed for the health care decision at hand, in order to respect the patient's interest in privacy.

Bases of decision: In the case of a proxy directive, a proxy would be expected to decide about health care in a way calculated to serve the patient's best interests. Although that concept is an elastic one, the law of each state gives it some meaning, and it has received extensive attention in legal and philosophical commentary.<sup>25</sup> Ought the concept of best inter-

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a skilled nursing facility...at the time the directive is executed unless one of the two witnesses to the directive is a patient advocate or ombudsman as may be designated by the State Department of Aging for this purpose...." The explanation given by the legislature for enacting this provision is that some patients in skilled nursing facilities may be so insulated from a voluntary decisionmaking role, by virtue of the custodial nature of their care, as to require special assurance that they are capable of willfully and voluntarily executing a directive."

<sup>24</sup> The UNIFORM HEALTH CARE CONSENT ACT addresses this issue in several sections. Section 5 provides for a limited delegation of power by some individuals authorized to consent to health care for another under § 4(a)(2), (b)(2), and (b)(3). According to § 5, the only individuals authorized to consent for another who may delegate their decisional authority are *family members*. Nonfamily health care representatives, who may be appointed according to the terms of § 6, are not authorized to delegate their decisional authority. All delegations must be in writing, and unless the writing so specifies, no further delegation of decisional authority is permitted. Any delegated authority terminates six months after the effective date of the writing.

<sup>25</sup> See Joel Feinberg, *RIGHTS, JUSTICE, AND THE BOUNDS OF LIBERTY*, Princeton Univ. Press, Princeton, N.J. (1980); Ruth Macklin, *Return to the Best Interests of the Child*, in Willard Gaylin and Ruth Macklin, eds., *WHO SPEAKS FOR THE CHILD*, Plenum Press, New York (1982); A. M. Capron, *The Authority of Others to Decide About Biomedical*

ests be uniform, or should it vary, within certain outer limits, if the surrogate is the next-of-kin rather than a stranger? An instruction directive, whether by itself or joined with a proxy directive, creates the potential for decisions based upon the particular (and perhaps idiosyncratic) wishes of the patient. The interpretation of such a directive would seem to lie with the surrogate decisionmaker, particularly in the case of a proxy designated by the patient, at least in the first instance. Provision may have to be made, of course, for an administrative mechanism to decide situations in which a health care professional challenges the decision of a proxy on the ground that it is not based on the patient's best interests or on a reasonable interpretation of the patient's instructions.

**Administrative aspects.** Several procedural concerns probably need to be addressed in any statute for advanced health care directives.

**Triggering event:** A statute needs to specify how a directive becomes effective. Two sets of concerns are involved. The first, already mentioned, relates to the necessary guarantee that the directive reflects the wishes of the patient. Some of the "natural death" acts, for example, require that a directive must be executed after the patient has been informed of a diagnosis, so that the patient's instructions are arrived at in the context of the actual, not hypothetical, choices to be made.<sup>26</sup> Statutes also typically provide that the designation of a surrogate or the content of specific instructions be renewed every few years so that the signatory can reconsider the instructions or designation in light of changed circumstances or opinions.<sup>27</sup> Once it is determined that a directive is valid, a separate issue needs to be addressed: what makes it operative? A statute may leave that question to the document itself, to be specified by the person executing the directive. Or it may provide that a particular event or condition brings the document into play. In either case, the triggering event will require both a standard for action and a specification of who will make the determination. For example, a directive may become operative when a physician makes a particular prognosis ("terminal illness") or determines that a patient lacks decisional capacity regarding a particular health care choice.

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*Intervention with Incompetents*, in Gaylin and Macklin, *id.*; Joseph Goldstein, Anna Freud, and Albert J. Solnit, *BEYOND THE BEST INTERESTS OF THE CHILD*, Free Press, New York (1979).

<sup>26</sup> See Cal. Health and Safety Code § 7188 (Deering Supp. 1982); Idaho Code § 39-4504 (Supp. 1982); Or. Rev. Stat. § 97.055 (1981); Tex. Rev. Civ. Stat. Ann. art. 4590h § 3 (Vernon 1982).

<sup>27</sup> See Cal. Health and Safety Code § 7188 (Deering Supp. 1982); Del. Code Ann. tit. 16, § 2506(c) (1982); Idaho Code § 39-4504 (Supp. 1982); Or. Rev. Stat. § 97.055 (1981).

Revocation: Provision must be made for the process and standard by which a document can be revoked. The theory of self-determination suggests that as long as the principal remains competent, he or she should unquestionably have the power to revoke a directive. But what about an incompetent (incapacitated) person? The “natural death” acts have uniformly provided that *any* revocation by a principal negates a directive.<sup>28</sup> In the context of termination of life-sustaining treatment, that result may be sensible, since it would generally seem wrong to cease such treatment based upon a proxy’s orders when a patient, no matter how confused, asks that treatment be continued. In other circumstances, however, allowing revocations by an incompetent patient could wreak havoc on a course of treatment authorized by the proxy. Perhaps when a proxy does not believe he or she should be guided by a principal’s contemporaneous instructions, on the grounds that the principal is incompetent and is contradicting earlier competent instructions and/or acting against the principal’s own best interests, the question of whether to follow the proxy or the principal ought to be subject to independent review.

Review and safeguards: When disputes arise, either about the choice made by a proxy or about an attempted revocation by an apparently incapacitated principal, some means of review will be necessary to safeguard the patient’s interests. In some circumstances the review mechanism need only judge the process by which a decision has been reached. In other circumstances it may seem advisable to review the health care decision itself, which in turn may involve either a subjective or an objective approach to the patient’s well-being. In the absence of a special provision in the statute, questions of this sort would lead to review by institutional bodies and, eventually, to judicial proceedings.

In sum, serious issues need to be addressed, either in the applicability to health care of existing statutes created to resolve other problems, such as the durable power of attorney acts, or in the drafting or revision of statutes specifically to permit advance directives for health care. Many people are concerned that, as they become old or ill or especially if they are hospitalized, decisions about their health care will pass out of their hands and into those of health care professionals, who may be strangers to them. This widespread concern justifies

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<sup>28</sup> See Ala. Code § 22-8A-5 (Supp. 1981); Cal. Health and Safety Code § 7189 (Deering Supp. 1982); Del. Code Ann. tit. 16, § 2504 (1982); Idaho Code § 39-4505 (Supp. 1982); Kan. Stat. Ann. § 65-28,104 (Supp. 1981); Nev. Rev. Stat. § 449.620 (1979); N.M. Stat. Ann. § 24-7-6 (1981); N.C. Gen. Stat. § 90-321(e) (1981); Or. Rev. Stat. § 97.055 (1981); Tex. Rev. Civ. Stat. Ann. art. 4590h § 4(a) (Vernon 1982); Wash. Rev. Code Ann. § 70.122.040 (West 1982).

continued attempts to find a simple way to extend at least basic self-determination into a period of decisional incapacity. Although the issue has received particular public attention in the context of terminal illness,<sup>29</sup> it is not limited to that setting, and there are good reasons to treat the entire subject of advance directives within a single statute. Without endorsing any particular statute, the Commission does endorse the development of advance directives and encourages patients and professionals to use them as appropriate whether or not there is a specific statute that regulates and enforces their use.

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<sup>29</sup> Indeed, the subject receives further attention from the Commission in its forthcoming report on deciding about life-sustaining therapy.